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Liminality, possibility, and imperative

Performing the other in face transplantation

Samuel Taylor-Alexander

Abstract

This piece seeks to expand the notion of liminality within medical anthropology by shifting attention to how in-between states are actively produced and performed by medical experts. While medical anthropologists have successfully engaged with the notion of liminality to make sense of patient experience, I suggest that it holds broader potential and can be used to examine the production of medico-political imperatives by clinical elites. To do this, I trace shifting ideas surrounding the need to utilize face transplantation as it relates to the promotion of an institutionally produced category – the ideal patient. While once the 'ideal patient' was seen as a panacea to the ethical issues at stake in the performance of the operation, it arguably now works to limit the ability of surgeons to utilize face transplants to reconstruct the appearances of severely disfigured people. In response, leading face transplant surgeons tactically emphasize the problematizing state of their patients who occupy the limen of life and death. They ascribe sick roles to individuals in order to afford agentive, moral force to (bio)ethically fraught experimental medicine.

Keywords

Liminality, face transplantation, bioethics, medical imperative

In the lead-up to performing the first face transplantation in the United States, Dr. Maria Siemionow of the Cleveland Clinic provided a comparative study of facial versus kidney function, writing:

This comparison will ultimately show that the face is indeed an organ, with highly specific functions that enable human beings to negotiate the complex social routines that are essential for daily life. ... In sum, although transplantation of solid organs is essential for a patient's physical survival, face allotransplantation is essential both for physical and social survival. (Siemionow and Sonmez 2008, 346, 345)

The authors of this text implicitly state that the purpose of face transplantation is both to better the ability of patients to eat, breathe, speak, et cetera, and, in line with a broader movement in medicine, to improve the quality of life of the patient. They go so far as to suggest that the former is all but worthless without the latter: 'Optimal social survival is what makes physical life worth living (Siemionow and Sonmez 2008, 345). Face transplantation is presented as akin to other forms of organ transplantation with the superadded benefit of social survival.

Publications in professional medical journals, such as the one above, emphasize the problematic status of patients with severe facial deformities. These texts promote a confluence between the face, biological life, and a life worth living. In doing so, they emphasize the problematic status of patients who, without the operation, we are told, will continue on in the sick role. In an article entitled 'A Position Paper in Support of Face Transplantation in the Blind' the authors, from Boston's Brigham and Women's Hospital, write:

The centrality of the face is universally recognized; as noted by Alexander, 'The face is essential. ... [I]t is the essence of the person it identifies and a mark of shared humanity'. The capacity of the face to manifest this quality is derived from its status as a conduit for multiple functionalities far in excess of its aesthetic dimensions; indeed, the face simultaneously provides the means to effect oral competence, olfaction, phonation, ocular protection, air humidification, nonverbal communication, expression of emotion and sexuality, perception, and the conveyance of social information. (Carty et al. 2012, 319)

In this extract, the face is presented as fundamental to social and biological life; individuals with severe facial disfigurement are discursively coded as nonpersons that exist outside of shared humanity. They are liminal beings, we might say, and their status makes imperative the need to intervene in a way that will restore their personhood and allow them to participate in the human world. In this essay I develop the notion of liminality by drawing attention to the reflexive construction of patients as incomplete human beings.

I have recently joined an interdisciplinary team that is engaging the concept of liminality to examine regulation and health research, in order to explore the spaces between policy and practice. This has challenged me to move back to again analyze the relation between ‘is’ and ‘ought’ in face transplantation, between ideal patients and the imperative to treat them using the procedure.¹ In his seminal study, Victor Turner (1969, 95) writes that liminal objects, people or other material entities, move ‘through the network of classifications that normally locate states and positions in cultural space. Liminal entities are neither here nor there; they are betwixt and between the positions assigned and arrayed by law, custom, convention, and ceremony’. Medical anthropologists have utilized the notion of liminality to make sense of sickness and the corresponding stigma experienced by people whose conditions problematize fundamental ideas in biomedicine and corresponding notions of personhood (for example, Honkasalo 2001; Jackson 2005; Jaye and Fitzgerald 2012). Drawing on Turner’s work, literary theorist Susan Squier (2004) similarly argues that a central feature of ‘liminal lives’, such as ‘excess embryos’ resulting from in vitro fertilization, is how they inherently trouble existing categories of being. In revealing the instability of social categories, liminal entities threaten established social order and thus become the site of reflection, governance, and political action. Following these studies, I offer up a thought experiment, at the center of which is a question: what if liminal states are discursively produced and performed in proxy by medical experts in order to evoke a sociopolitical response?

Many anthropologists examining questions of biotechnology have come to draw on the work of Italian philosopher Giorgio Agamben (1998) who reminds us there was no single word for describing ‘life’ in the Greek philosophical tradition. Rather, they employed two semantically different terms: ‘*Bios*’ referring to an appropriate form of life for groups and individuals that is inherently social, and ‘*Zoē*’, or ‘bare life’, the simple act of being alive. This distinction has proved fruitful in ethnographic analyses, drawing scholarly attention to how contemporary notions of ‘life’ are continually problematized and remade with scientific and technological developments. As Paul Rabinow (1999) has written, it is increasingly apparent that this classical distinction is itself being outmoded by contemporary scientific

¹ I have written extensively about how the delineation of patient types has been a central feature in ‘making ethical’ face transplant surgery (Taylor-Alexander 2014a, 2014b). This writing was based on my interviews with a team of Mexican surgeons and legal specialists, who developed Latin America’s first face transplant protocol, alongside publications by patients, bioethics personnel, and medical experts. Doing this allowed me to show how the confluence of material technologies, human biology, institutionalized forms of reason (bioethics), and longstanding professional imperatives (the Hippocratic Oath) resulted in a new kind of patient: the ideal face transplant candidate.

biomedicine. We might say that, through surgeons like Maria Simeionow, face transplantation has brought *Bios* and *Zoë* into a particular relationship: in emphasizing that patients with severe deformities occupy a liminal space between life and death, face transplantation calls into question the responsibility of biomedicine and corollary state institutions to provide the operation to patients.

The centrality of the face in the making of the industrialized human subject has been the site of intense reflection and scrutiny.² While these works differ on whether the face has an inherent character that truly represents the individual self, collectively they demonstrate that the face is embedded and manipulated within hierarchical sets of sociopolitical relationships. The face has emerged as key to everyday modes of understanding self and other, and is thus often the site of manipulation and management (Butler 2006). Gilles Deleuze and Felix Guattari (1987) write of ‘facialization’, the historical (over)coding of the face as representing the self that marginalizes any competing attempt to reimagine a human identity vis-à-vis the body as a whole. The face, they write, ‘is not content to cover the head, but touches all other parts of the body’ (Deleuze and Guattari 1987, 170, emphasis in original). Moreover, as a sociopolitical ‘machine’, the process of facialization that posits the face as the marker of the self is central to the making of the capitalist subject.

While there is much of interest in this body of literature, I want to draw attention to the centrality of the face to our understandings of the human self and how this is being reproduced in and by face transplantation. Face transplantation involves removing a composite graft of hard and soft facial tissue from a brain-dead donor and transplanting it to a person whose face has been damaged through trauma such as a gunshot wound or animal attack. Reconstructive surgeons transplant autologous tissue (the patient’s own tissue) on a daily basis. The particularities of trauma or congenital malformation often require them to move, reshape, and repurpose parts of an individual’s body in order to reconstruct the patient’s face. Face transplantation was first proposed as a means to overcome the limits of surgical reconstruction connected to the unavailability of sufficient and appropriate biological tissue for surgical restoration. That is, face transplantation was proposed as a therapeutic option for patients whose face could not be completely restored using traditional reconstructive methods.

From the outset, the suggestion of offering the procedure provoked ethical concerns because, as with the transplantation of solid organs, patients would be required to commit to

² Thinkers including Emmanuel Lévinas (1985), Gilles Deleuze and Felix Guattari (1987), and Judith Butler (2006) have all spent significant time reflecting on the importance of the face in contemporary forms of sociality.

a lifelong course of potentially fatal immunosuppressant therapy in order to counter biological rejection of the transplanted graft. While concerns were raised about how patients would cope with living with another person's facial tissue in place of their own, the key ethical question that was raised can be phrased in the following way: 'Is it ethical to offer patients with non-life (biologically) threatening conditions a potentially fatal treatment in order to improve their quality of life?' At stake in this question are broader issues of what kind of life it is that patients with mutilated faces have and what can and should be done, within established forms of ethical reason, to offer them an appropriate form of life. Moreover, the technological capacities related to the surgery reframed the lives of potential patients, transforming them into the object of political, medical, and ethical reflection.

In face transplantation, those in favor of the procedure strategically emphasized how potential patients existed as incomplete persons whose social life made their physical life not worth living. But the dependence on immunosuppression to counter transplant rejection risks destroying patients' existing biological life, compromising the Hippocratic Oath that underlies medical ethics: 'first, do no harm'. A broad consensus was reached within the medical community that if face transplantation was to occur then only certain patients could ethically be operated upon. In order to mitigate the prevailing epistemic and ethical constraints surrounding the procedure, a new type of 'ideal patient' was constructed. The psychology of the face transplant patient, and their biology, must exhibit certain qualities, must exist in a certain balance between normal and pathological. It is in this balance that they become operable and ethical because they conform to the very guidelines and arguments that (re)produce them in light of current epistemic, ethical, and technological practices (Taylor-Alexander 2014a).

The Royal College of Surgeons, for example, offered an overall cautioning of the use of the procedure while introducing specific guidelines for selecting 'suitable candidates for face transplantation'. These were organized into six key points: (1) the patient's motivation for seeking the treatment and their expectations of the outcome; (2) their prior engagement with other, 'less risky' potential solutions, especially psychological intervention; (3) the psychological stability and capacity for readjustment of the prospective patient: they 'should be sufficiently resilient to cope with the considerable stress associated with the transplant, including the "unknowns" associated with a new procedure of this nature, the complex immunological and behavioral post-operative regimen, [and] the risks of rejection'; (4) their 'level of cognitive functioning ... should be sufficiently good to understand and assimilate complex risk/benefit information'; (5) the patient must demonstrate 'adherence credentials'; and (6) the patient must have a strong social support network in order to 'buffer' them against stresses during and after the procedure (Royal College of Surgeons, 2006, 16).

In my work in Mexico, I was interested in the category of ‘ideal patient’ as a boundary object, as something that was both flexible enough to travel between different institutional (and international) settings, and stable enough to remain significant and influential as it did so (Star and Griesemer 1989). This drew my attention to how the frame altered the relation between a team of reconstructive surgeons and one of their patients: it produced a sense of obligation to develop a face-transplant protocol in order to be able to use the latest medical therapeutic to treat patients. These surgeons reworked the selection guidelines offered by the Royal College of Surgeons, using them to classify groups of suitable and unsuitable patients (Taylor-Alexander 2014a).

While constantly aiming to understand what face transplant means *inter alia* for surgeons and for patients with facial disfigurement, I have endeavored to remain critical of the operation. In a written interview with a freelance journalist from Reuters Health, I was asked about my thoughts on whether the operation should be taking place, considering the fatality rate (then 11 percent). My unpublished response was as follows:

In allowing the operation to take place, all involved – patients, doctors, and institutional bureaucracy – are making a judgment call regarding not just the value of the operation as a therapeutic tool. Implicitly, they are commenting on the value of a life lived with a severe craniofacial condition. The value of such a life doesn’t appear very high when the medical community are willing to risk an individual dying in order to make them more normal, to offer them a life that correlates with what the Greeks called *bios*. Importantly, one could argue that in so devaluing such a life, face transplantation discursively grows in importance: the message is that restoring the anatomy of a person with such a condition is so important that it is worth risking death to achieve it, worth sacrificing a life lived with an abnormal face.

I include my above comments as an aid to this thought experiment. The delineation of an ideal patient type allowed surgeons and ethics boards to negotiate epistemic unknowns, minimize risks, and increase potential benefits, and ultimately allow face transplantation to pass as ethical. I have no fixed opinion as to whether the operation should be taking place; it is happening. Nonetheless, we need to be aware of its consequences, positive, fatal, and otherwise. We need to be aware and to take into account how face transplantation is remaking understandings of health and life along with the anatomy of patients. One consequence is an implicit change in the meaning of facial deformity. According to the reconstructive surgeons cited at the beginning of this piece, surgeons who are key actors in this emerging experimental field, face transplantation is life saving beyond other forms of organ transplantation. Together with their clinical efforts, they are marking people with incomplete appearances as incomplete persons, as subjects requiring intervention. The message that lies between the lines of their position statements and biological comparisons is that people without a complete, fully recognizable, and functional face exist in state of

permanent marginalization. In making this argument, they are reframing debate on face transplantation: it is no longer about improving quality of life; it is about saving the life of patients.

In his classic study of stigma and difference, Erving Goffman (1963, 3) describes how people with physical deformities are often thought about as incomplete, ‘tainted, and discounted’ persons. Extending this analysis through her ethnography of a New England chronic pain clinic, anthropologist Jean Jackson (2005) argues that stigmatization also occurs when people straddle established ontological boundaries (see also Becker 1963). Because they exist indefinitely in the sickness role, on the limen of life and death, chronic pain patients are:

ambiguous beings seen by those around them to threaten prevailing definitions of the social order [because] certain features of chronic pain result in the perception of sufferers as transgressing the categorical divisions between mind and body and as confounding the codes of morality surrounding sickness and health, turning them into liminal creatures whose uncertain ontological status provokes stigmatizing reactions in others. (Jackson 2005, 332)

In this passage, Jackson points to how chronic pain patients call into play established boundaries – between mind and body, health and sickness – deepening the stigmatizing impact of their condition.

With face transplantation, surgeons have strategically emphasized how potential patients exist as incomplete persons who straddle the limen of life and death. The actor network-based approach I used in my earlier analysis of the field revealed that the face transplant assemblage coproduced the ideal patient of face transplant surgery. Paying attention to the ontological uncertainty of such patients allows us to see how liminality is performed, emphasized, and seized on by doctors and surgeons in order to make imperative experimental medicine. Here we can draw a useful contrast between the example of chronic pain sufferers where their stigmatization results from their liminal status and its troubling of established boundaries such as healthy and sick, body and mind, and the status of face transplant patients.

The stigmatization experienced by people without complete faces, by ‘incomplete beings’, is stressed in order to produce a medical imperative. As surgeons like Siemionow and her peers suggested that the role of medicine is pointless if doctors cannot offer patients a life worth living, while noting that careful patient selection can move the risks and benefits of face

transplantation in favor of its performance, they came to further emphasize, and stabilize, the liminal status of persons with severe deformities. By symbolically deepening the stigmatizing dimensions of facial trauma, its dehumanizing effects were harvested as a resource to negotiate the ethical constraints surrounding the procedure. As a result, new categories of person were drawn up as potential recipients were classified using those categories; psychologists, social workers, and surgeons all examined the balance of health and sickness of their disfigured patients.

Medical anthropologists have developed the notion of embodiment in order to understand illness experience and the vicissitudes of what it is to have, and to be, a body. In thinking about the liminal status afforded to patients with facial disfigurement, I was reminded of an article by Carolyn Rouse (2004), in which she examines how parents and doctors struggle over the meaning and value of a dying child. In doing so, she offers the notion of ‘embodiment by proxy’ to draw attention to the ‘process of embedding oneself in a meaningful array of symbols’ in order to augment one’s (nonmedical) authority and status within a system of individual and institutional hierarchies:

As a concept, ‘embodiment-by-proxy’ relates to Webb Keane’s analysis of the development of semiotic ideologies, or how ideologies become embodied in ‘representational economies’ (2003: 423). These semiotic ideologies are, as Keane notes, ‘not just about signs, but about what kinds of agentive subjects and acted-upon objects might be found in the world’ (2003: 423). These signs have the potential to instigate action and, therefore, they have material force [...] For the parents of this dying child, the unstated hope was that, through association with particular signs and the reshaping of their own dispositions, they would clarify their moral character to those with the power to keep their child alive. (Rouse 2004, 515)

In this example, Rouse draws our attention to how individuals in the clinic are able to tactically perform and align their bodies and self within a ‘representational economy’ in order to alter the symbolic weight value of the life they care for.

In drawing on and reinscribing the relationship between face and self, transplant surgeons have, similarly, been engaged in a process analogous to the ‘embodiment by proxy’ described by Rouse. They have been performing the liminality of patients with disfigurement, moving them to a space on the threshold of life and death. The face is made ‘to cover the entire body’ when it is presented as the common essence of humanity and as central to complete personhood. In their writing on faciality and *la puissance du visage*, Deleuze and Guatarri (1987, 175) state: ‘We are certainly not saying that the face, the power of the face, engenders and explains social power’. Rather, examining how the face has come, and continues, to stand in for the self is presented as an avenue to understand contemporary forms of subjectification. Liminal subjects reveal and in doing so threaten existing social structures, becoming the site

of intense scrutiny and reflection. Using the notion of liminality to rethink the relationship between 'is' and 'ought' in face transplantation, between ideal patients and the imperative to operate, I have come to meditate on the role of marginalized selves in the reproduction of medical legitimacy and the production of technical need. While medical anthropologists have successfully engaged with the notion of liminality to make sense of patient experience, I wish to suggest that it holds broader potential and can be used to examine the production of medical imperatives. At the very least, it provides a useful lens for thinking about how sick roles are inscribed in individuals in order to afford agentive, moral force to (bio)ethically fraught experimental medicine.

About the author

Samuel Taylor-Alexander is Senior Research Fellow in Medical Anthropology at the School of Law, University of Edinburgh. He has taught anthropology at the University of Auckland and the Australian National University, and has held visiting positions at Harvard University and the University of Copenhagen. Samuel is the author of *On Face Transplantation: Life and Ethics in Experimental Biomedicine* (Palgrave Macmillan, 2014).

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